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ABSTRACT

This instructor's manual is designed for those coordinating inservice training programs for personnel involved in the education of young handicapped children which use Module I of the cluster of instructional modules for competency based teacher education. It offers suggestions for preparing for instructional activities, evaluating the pre- and post-assessments, and evaluating the module's activities. (MM)

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PARENT INVOLVEMENT IN THE EDUCATION
OF
YOUNG HANDICAPPED CHILDREN

MODULE I:

FAMILY REACTIONS TO THE HANDICAPPED CHILD

SHIRLEY COHEN

HUNTER COLLEGE

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INTRODUCTION

Why This Module Cluster?

There are many aspects and stages in learning to work with parents of the handicapped. Before a teacher of handicapped children can work effectively with parents she must understand and empathize with the special feelings and responsibilities which these parents experience. She must understand the role which parents play in their children's learning. She must be aware of ways in which parents can and have been effectively involved in their children's education. She must understand the special dynamics and cautions of relating to individual parents and families.

This module cluster, or series of related modules, was the vehicle selected for reaching the above multi-faceted goals. Each of the three modules in the cluster attempts to get at a major stage in this learning process.

Utilization Conditions

This module cluster presupposes a responsible individual--usually the course instructor--who will serve as instructional coordinator. His responsibilities are to plan for the availability of materials, help trainees arrange instructional activities, be available for individual consultations and group discussions, and evaluate pre-assessment and post-assessment results with the trainees.

ADMINISTERING THIS MODULE

Format of Module I

Unlike most modules, this one provides few choices with regard to instructional activities. (Some choice of reading matter is provided in Element I.) The goals of this module are affective and exploratory as well as cognitive. No alternatives to first-hand experiences in the homes of handicapped children were provided because it was felt that there were no equivalent instructional activites. However, this module does allow for different entry levels. Pre-assessment results will determine whether the trainee undertakes all instructional activities, skips the readings, or exits and goes directly to Module II.

Deciding on an Entry Level

Entry Level I: For trainees who do not satisfactorily answer questions 1-5 on the pre-assessment. All instructional activities must be completed.

Entry Level II; For trainees who satisfactorily answer questions 1-5 but not 6 and 7 on the pre-assessment. The trainee skips Element I and begins with Element II, completing all instructional activities that follow.

Direct Exit: Trainees who satisfactorily answer all questions on the pre-assessment may go immediately on to Module II.

Preparing for Instructional Activities

As instructional coordinator for this module, you will have to develop a mechanism and procedure for finding families of young handicapped children to participate in the training activities involved. The following organizations may be of help to you:

1. Alexander Graham Bell Association for the Deaf - International Parents Organization
2. American Foundation for the Blind
3. The Association for Children with Learning Disabilities
4. Epilepsy Foundation of America
5. Muscular Dystrophy Asscciations of America, Inc.
6. The National Association for Retarded Children
7. The National Easter Seal Society
8. The National Foundation - March of Dimes
9. National Society for Autistic Children
10. United Cerebral Palsy Associations

Local educational agencies may also be of help in obtaining families for participation.

Evaluating the Pre- and Post-Assessments

Since the pre-assessment and post-assessment are the same, use the following guide in evaluating both.

Question #1:

List and describe briefly the typical sequential reactions of parents to the recognition that their child is "different" (handicapped).

Response:

A list of sequential reactions is given on page 10 of the Overview for this module. For discussion of these reactions, see the footnoted references on that page. A satisfactory response to this question would include a description of at least four of the seven reactions listed on page 10.

Question #2:

Briefly describe three common stresses in the everyday life of a family with a five-year-old handicapped child which are either absent or much less intense in the family with a normal child of the same age.

Response:

A list of common stresses is provided below. However, trainees cannot be restricted to three responses from this list. Use your own judgment as to the value of responses you may receive that are not on the list below.

2.1 Constant fear that the child will hurt himself because of his limited understanding of danger and of how things work.

2.2 Necessity of helping the child with all aspects of self-care, including toileting, feeding, dressing, bathing, grooming.

2.3 Difficulty in getting babysitters or in enlisting relatives to care for the handicapped child so that the mother can get "a break" from time to time.

2.4 Worry about and anger at child's rejection by other children and adults in the neighborhood.

2.5 Difficulty in finding a suitable educational program for the child.

2.6 Difficulty in arranging for transportation for a physically handicapped child, and architectural barriers which prevent this child from access to many public places.

2.7 Difficulty in finding appropriate recreational programs.

2.8 Tendency of some professionals and lay people to blame the parents for the child's disability.

2.9 Difficulty in communicating ideas to the child and in teaching him new things that he needs to know in order to function more independently.

2.10 Child's great dependence upon the mother, psychological as well as physical, and great fear of separation.

2.11 Frequent medical care which the child may need.

2.12 The bizarre behavior of the child which the parents can't understand and which causes them shame and/or grief.

Question #3:

Briefly describe two attitudinal (social-emotional) achievements and two cognitive achievements which the young, mildly-to-moderately handicapped child in a "coping" family often learns at home.

Response:

Possible answers include the following:

3.1 Attitudinal (social-emotional) achievements

a. Self-knowledge--sense of self. Development of tastes, interests.

Self-acceptance -accepting his limitations.

b. Movement toward other children.

c. Achieving maximum independence in functioning that is possible in view of handicap. Wanted to achieve this himself.

32. Cognitive achievements

a. Acquisition of basic vocabulary needed in school learning.

b. Rote counting.

c. Interest in doing puzzles.

d. Interest in using crayons.

e. Interest in having picture books read to them.

Question #4:

Briefly describe three long-term concerns frequently associated with being the parent of a handicapped child.

Response:

4.1 Will my child survive or will his disease/defe ^ use him to die?

4.2 What will happen to my child if (when) I die? Who will take care of him? Will he be able to function without me?

4.3 Will my child be able to have a social life, marry, have children?

4.4 Will my child be able to be educated?

4.5 Will my child be able to get a job and support himself?

Question #5:

Write a brief description of two examples of parents whom you know or have read about who have made extraordinary efforts on behalf of their handicapped children and/or other handicapped children.

Response:

The response to this question should reflect one of the following:

5.1 Long-term, constant devotion to helping the child "make it" in a way far beyond the usual expectations for such a child. Example: The mother of the severely language-impaired and disordered child in "The Birth of Language."

5.2 Long-term, constant devotion to a severely, multiply handicapped child.

5.3 Long-term devotion to a "cause" for the handicapped. Example: The father in "My Search to Find the Drug That Crippled My Baby."

Question #6:

Imagine yourself the parent of a five-year-old boy with Down's Syndrome on a visit to a neighborhood playground with your child. In what ways might you feel differently about making this excursion than would the parent of a "normal" child? Why?

Response:

Most or all of the following points should be included:

6.1 Presence of a general fear (anxiety) that he will be rejected by other children and their parents.

6.2 Fear that he may hurt himself because he has no understanding of danger.

6.3 General discomfort because you perceive people to be looking at you with sorrow or aversion.

6.4 Tension over the possibility of people making derogatory remarks and children mocking your child.

6.5 Determination that your child will not be treated badly by other children or adults.

6.6 Hopefulness and eagerness to make this a positive social learning experience.

Why

6.7 The mother or father may have mixed feelings about the child and about being the parent of a handicapped child.

6.8 Past experiences may have led her or him to expect (anticipate) the problems referred to in 6.1 - 6.4.

Question #7:

On the basis of observations in the homes of two young handicapped children with whom you have worked, and interviews with their families, compare the two families on the following dimensions:

a. emotional flavor and child-rearing approach (attitude)
b. coping ability of the family
3. daily investment of time and energy in furthering the handicapped child's development and achievement
4. management techniques (behavioral control or discipline)

Your answer should:

a) Identify possible effects of these reactions
b) Include data from observations, interviews and/or readings to support conclusions.

Response:

Since the response to this question must be related to the particular experiences of each trainee, only criteria for evaluation are provided. The major criteria for evaluating responses are

7.1 How specifically the responses address the question.
7.2 How well conclusions are supported by observational and/or interview data.
7.3 How well responses reflect knowledge of the literature about parents of the handicapped.

Evaluating Activities

Element I: Answers are given in the Module Appendix. Trainees are to check their own responses.

Element II, Activities 1 and 2: Because these reports are based upon first-hand observations and interviews, the contents will vary from trainee to trainee. It is therefore not possible to give a standard correct answer. The primary criteria for evaluating the report on Activity 1 (observation) should be the relevance and specificity of the conclusions to the dimensions on the Observation Guide, and the closeness of the conclusions to the observations offered to support them. The primary criterion for evaluating the report on Activity 2 (interview) is the strength of the connections made between interviews and observational data.

You should evaluate the trainee's first observational report before he or she completes the second one. The same procedure should be followed for the interview reports. In the case of those trainees whose first reports are satisfactory, you need not evaluate the second reports yourself. You may, instead, arrange to have a small number of trainees meet to evaluate each other's reports in a group, utilizing the same criteria that you used. You should, however, personally evaluate the second reports of those trainees whose first reports were unsatisfactory. You may also want to ask them to revise their first reports, either in writing or orally--in conference with you--before going on to the second reports.

Element III, Activities 1 and 2: You are not to evaluate the reports on these activities. They are to be used by the trainees as the basis for their contribution to the discussion in Element IV.

As an additional activity for Element III, you might want to obtain the film - Stress: Parents with a Handicapped Child (Mental Health Film Council). It runs 30 minutes and is available from the N.Y. U. Film Library for $13.

Element IV: Evaluation of the reports written for Element III, as well as of the trainees' feelings and attitudinal changes, should be undertaken jointly by you and the trainees in the discussion seminar.

The major purpose of this discussion is to give trainees the opportunity to examine their feelings towards parents of the handicapped and exchange ideas about what these feelings were before, during, and after participation in the instructional activities of this module. The discussion should begin with a focus on the two activities of Element III. The specific questions included in the guides to the reports for these activities might also be used to guide the discussion. Trainees should be asked to have their reports available to refer to during the discussion.

Some of the ideas listed below might be discussed, too, in light of the trainees' experiences in Elements I and II.

1. The qualities and characteristics of a family which can cope with and maximize the growth of a handicapped child.

2. The special strains of the low-income family with a handicapped child.

3. What the trainees have learned from parents about how handicapped children develop, function, and learn.

Module Cluster: Cohen, S. Parent Involvement in the Education of Young Handicapped Children

The field testing of these modules has provided data about specific content or format that could profit from clarification elaboration or revision. Module users may find the suggested refinements discussed below of assistance to them in the implementation of the module in particular instructional settings.

The modules in this cluster were well received. Not only did the students feel that the competencies they acquired were important ones for teaching but they were especially positive about the learning activities and rated them between Good and Very Good. The refinements suggested by the field test results are designed primarily to:

1. Ease the work load.
2. Broaden the concepts developed to include appropriate exemplars from disadvantaged populations.
3. Provide more sophisticated assessment measures.
4. Make judicious use of videotaped segments to heighten understandings in the affective domain.

Module I: Family Reactions to the Handicapped Child

Pre-Assessment

The questions need to be rewritten to provide a more valid measure of student competence. They should be pegged at a higher taxonomic level to allow for some measure of depth of understanding and the possible existence of preconceptions or misconceptions which need to be deal with in working through the module.

Element I

Many students felt that the readings were one-sided declarations of successful accomplishments. The instructor could supplement the readings with speakers, video-tapes, films, etc. that would draw on parent experiences in ghetto populations and child care worker experiences in institutional populations. Readings on the normal child also need to be included. To consolidate the learnings students favored a large group discussion over the written responses to questions as suggested in the module.

Elements II, III

Many students have had difficulties in making their own arrangements with families of handicapped children. The instructor should be prepared to assist students in arranging for family placements and helping them to be at ease in the interactions. It would be desirable to have these placements cover a wide range of handicaps and all SES levels. This would provide a broad range of experiences to be shared in Element IV. The work load can be eased by requiring only one family placement and one observation in Element II and one activity in Element III.

The working of the objectives of Element II need to be revised to be consonant with the activities. They should read as follows:

1. You will satisfactorily describe the parent-child interaction on the five dimensions listed in the Observation Guide.

2. You will satisfactorily compare the relationship between the parent-child behavior you observed with the responses given by the parent during an interview.

Element IV

A video-tape of an experience from Element II or III could be used effectively to begin the discussion. One of the objectives of this discussion should be the effect of a family reactionpattern upon a child's teachability.

Post-Assessment

See Pre-Assessment notes.